Action against Asthma

A Strategic Plan for the Department of Health and Human Services

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Executive Summary

Asthma: Epidemic of a Chronic Disease

Asthma is a chronic inflammatory disease of the airways. Over the past 15 years, the number of Americans afflicted with asthma has more than doubled to an estimated 17 million, with the increase in rates highest in children under five years old. Two factors classify asthma as an epidemic that by all indications is continuing: the steady rise in both the proportion of people getting asthma, and the severity of illness for people who already have the disease. Although asthma affects Americans of all ages, races, and ethnic groups, low-income and minority populations experience substantially higher rates of fatalities, hospital admissions and emergency room visits due to asthma.

Even if rates were to stabilize, asthma would continue to be a significant public health problem and the most common chronic disease of childhood, affecting an estimated 4.8 million children. Asthma is one of the leading causes of school absenteeism, accounting for over 10 million missed school days annually. Symptoms not severe enough to require a visit to the emergency room or to a physician can still substantially impair quality of life. Asthma results in many lost nights of sleep and disruption of family and caregiver routines. Over one third of people with the disease restrict their activities. Taking care of asthma is expensive and imposes financial burdens on patients and their families, including lost work days and income, as well as job opportunity. Asthma is the leading work-related lung disease, accounting for at least 21 percent of all adult onset asthma. In 1990, the cost of asthma to the U.S. economy was estimated to be $6.2 billion, with the majority of the expense attributed to medical care. A recent analysis using different methods estimated the cost of asthma in 1996 to be $14 billion.

Critical breakthroughs in science in the last decade have generated a body of information that, when effectively used to guide care of patients, enables most people with asthma to live fully active lives. The National Asthma Education and Prevention Program (NAEPP), sponsored by the National Heart, Lung and Blood Institute (NHLBI), developed Guidelines for the Diagnosis and Management of Asthma (”*Guidelines*”) which translate the scientific findings into recommendations for patient care. When the *Guidelines* are followed, health care providers, caregivers, and patients with asthma work together to control the disease. Appropriate medical care and self-monitoring of symptoms along with measures to control allergens and other triggers in the indoor environment — described in the *Guidelines*— can substantially reduce the frequency and severity of asthma attacks.

Yet, many patients remain ill because of a complex interplay of factors. One impediment is that many patients are still not being treated or educated ac-

cording to the *Guidelines*; another is patients' lack of access to quality medical care or resources to obtain sufficient medications or equipment. For example, a recent study found that one out of five children in Baltimore, MD and Washington DC were receiving the wrong or no treatment for asthma. Even with high quality care, some cases of asthma are particularly difficult to control, and medications cause adverse side effects in some people. Moreover, lack of timely surveillance data at the State and local levels impedes planning of intervention efforts[1]. Finally, research results have not yet pointed to strategies to prevent asthma from occurring in the first place. The genetic basis of susceptibility to asthma and the biologic mechanisms that explain the interaction of susceptibility and environmental exposures are not well understood.

An array of activities—promoting effective implementation of the *Guidelines*, ensuring access to quality medical care, enhancing surveillance and intensifying research across the spectrum from molecular biology to health services delivery—implemented at an accelerated pace—holds great promise for reducing the chronic burden of asthma and reversing the steady increase in rates.

DHHS Capacity to Address Asthma

The Department of Health and Human Services (DHHS) conducts and supports research, public health practice, and health services delivery to address the growing problem of asthma[2]. In Fiscal Year 1999, DHHS will invest over $120 million in asthma research. DHHS-supported grantees have been responsible for many of the scientific breakthroughs that helped shape the *Guidelines*. DHHS spends much more on direct delivery of medical care: estimates of Medicaid and Medicare expenditures for treatment of asthma exceed one billion dollars per year. DHHS funds research to study the quality of care received by individuals with asthma and could expand its evaluation of asthma care. To date, relatively few dollars (less than five million) have been spent on public health practice for asthma. With those funds, the Department has supported partnerships that are discovering new ways to increase dissemination to and use of information by communities, health care providers, patients and their families.

Secretary's Initiative on Asthma

In the fall of l997, DHHS convened a high-level workgroup to assess the most urgent needs and opportunities for tackling the growing problem of asthma. Shortly thereafter, an Interagency Task Force on Environmental Health Risks and Safety Risks to Children, co-chaired by Secretary Shalala and Environmental Protection Agency Administrator Browner, decided to take immediate action across the government to address the environmental aspects of childhood asthma. At the Secretary's request, the DHHS workgroup developed a Department-wide strategy encompassing all age groups affected by asthma and the many factors—in addition to environment—influencing this disease. The DHHS initiative is closely coordinated with the activities of the Task Force.

[1] Surveillance is the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation and evaluation of public health practice (1). A surveillance system includes the functional capacity for data collection and analysis as well as the timely dissemination of these data to persons who can undertake effective prevention and control activities (2). Public health officials use surveillance to understand changes in rates of disease in different locations or populations, to help evaluate medical care and public health programs, and to identify clues about risk factors.

[2] Public health practice activities are those that facilitate the work of the medical community and others to prevent asthma cases, reduce the severity of symptoms and improve the quality of medical care. Public health practice typically includes development of educational materials, training and coalition building, and could include work with local and state environmental agencies. Public health practice is distinct from, but complimentary to, direct provision of health services.

Four Priorities for Investment

- ➢ Determine the causes of asthma and develop interventions to prevent it from developing in the first place.
- ➢ Reduce the burden for people living with asthma.
- ➢ Eliminate the disproportionate burden of asthma in minority populations and those living in poverty.
- ➢ Track the disease and assess the effectiveness of asthma intervention programs.

The strategy envisions close coordination between DHHS initiatives and activities led by universities, non-governmental and community-based organizations, private industry and other government agencies in pursuit of progress in these areas over the next five years.

"My asthma attacks are very different depending on whether they are exercise-induced or triggered by an allergen or irritant. When I'm running, I get hints of an asthma attack when the rhythm of my breathing starts to change. After that, the real struggle to breathe starts. I feel like I'm fighting with some unknown force for each breath. Sometimes, I feel like the air comes into my mouth but will not go down into my lungs, and all the breathing is in vain. Other times, it feels like all the air is coming into my lungs, but nothing is coming out. My lungs feel as if they're going to explode. I'm lightheaded and weak. My whole upper body gets tense and I feel frightened and panicked which makes things worse. Attacks not caused by athletics seem to come on more gradually but also feel like I'm not getting enough air with each breath. It's a full body workout to take each breath. My chest tightens up a lot and it either feels like I have 1,000 pounds of bricks on my chest or that someone has their hands on my lungs and is squeezing with all their might."

-An eighteen year old asthma sufferer

"My son has had chronic asthma since he was 18 months old. That means we ask the same questions again and again: Did you do your second puff [i.e., medication]? Did you rinse your mouth? Have we packed the nebulizer? Do we have the prescription for the medication on hand? It means his dad and I stay watchful because every season brings its own danger: pollen in the spring, heat and air pollution in the summer, leaf mold in the fall, and infection in the winter. It means that everyday events like soccer practice, visits with friends who have cats, and even hay rides require vigilance. Most of all, it means a cough is not just a cough. It can be the first cough in a long day and night punctuated every 10 seconds with another sharp little cough.

One of the hardest things about being a parent of a child with chronic asthma has been to acknowledge to myself that asthma, for my son, is chronic. It is not a temporary thing. Another difficult thing has been to deal with the symptoms and treatment of his asthma without making him feel different. And finally, the emotions are hard too. Not just the niggling fear but also, the surprising anger—Why do some doctors seem to know so little about prevention and asthma management?"

-A young mother

Overview

Epidemic of a Chronic Disease

The Growing Problem of Asthma

Asthma is a chronic inflammatory lung disease characterized by recurrent episodes of breathlessness, wheezing, coughing, and chest tightness, termed exacerbations. The severity of exacerbations can range from mild to life threatening. Both the frequency and severity of asthma symptoms can be reduced by using medications and reducing exposure to environmental triggers.

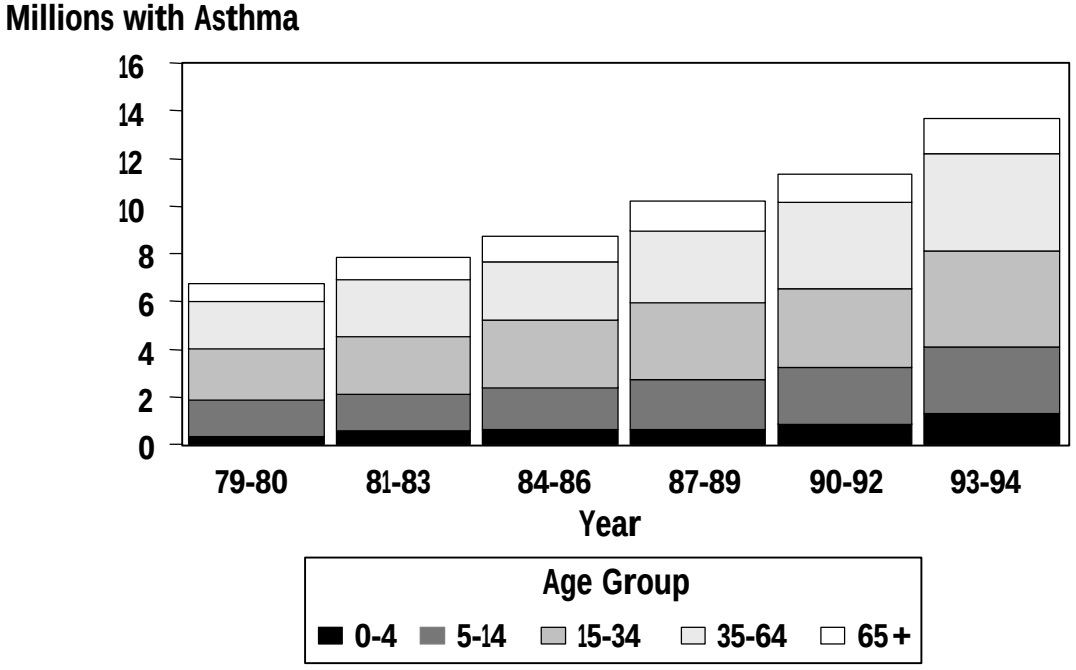
Many people with asthma experience symptoms and substantially impaired lung function only during exacerbations. However, for many of these patients as well as for those with persistent asthma, ongoing preventive management is needed. Learning how to manage asthma as a chronic disease is a major challenge for patients, as well as for health care providers and others involved in asthma care.

For the past 15 years, an epidemic of asthma has been underway in the United States. Two factors classify asthma as an epidemic that by all indications is continuing: the steady rise in both the proportion of people getting asthma and the severity of illness for those who already have the disease. Although asthma affects Americans of all ages, races and ethnic groups, children, low-income and minority populations have been particularly severely affected[3].

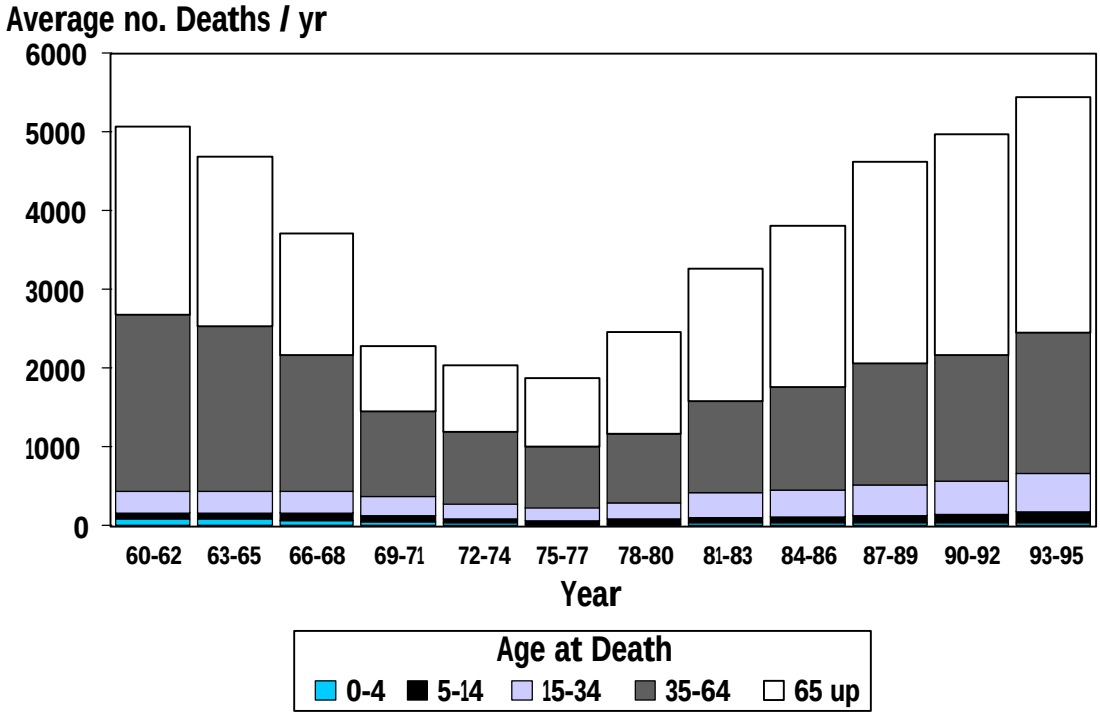
National survey data—the responses of randomly selected US residents being asked whether they had symptoms of physician-diagnosed asthma in the previous 12 months— indicate that the number of people with asthma in the United States has more than doubled in the past 15 years. In 1980, 6.8 million Americans had asthma. By 1996, the most recent year for which data are available, the number had risen to 14.6 million (3). Based on these trends, the Centers for Disease Control and Prevention (CDC) estimate that, in 1998, as many as 17.3 million people in the United States have asthma (4). Rates of asthma are increasing in all age groups, among both men and women, and across all racial and ethnic groups. Total deaths from asthma have also risen, from a low of 1,674 in 1977, to 5,637 in 1995 (5).

[3] Although national data do not provide the resolution necessary to identify particular geographic areas hardest hit by the asthma epidemic, surveys undertaken in a number of large cities in the United States indicate that the prevalence and severity of asthma are greatest in the medically underserved, inner city. A large proportion of inner-city families are insured through Medicaid.

Prevalence of Asthma, United States, 1979-1994



Deaths Due to Asthma, United States, 1960-1995



Even if the increase in rates were to stabilize, asthma would remain an important public health problem and the most common chronic disease of childhood, affecting an estimated 4.8 million children (6). In the United States, the prevalence of asthma is slightly higher in boys than in girls under age 18. Among adults, women of all races suffer greater asthma mortality and morbidity than men. Asthma is more common in school-aged children than in preschool-aged children or adults. However, the most rapid increase in cases of asthma are occurring in children under five years old, with rates increasing over 160% over the last fifteen years (5).

Disproportionate Burden of Asthma Among Minority Groups

In the most recent years for which data are available, African Americans were more likely to have asthma than were whites, with rates of 58.8 per 1,000 population and 50.8 per 1,000 respectively (5). Although the rates of death have increased among all age and racial and ethnic groups, African Americans are much more likely to die from asthma than whites (5). From 1993 through 1995, the death rate from asthma in African Americans—38.5 per million—was over twice the rate of 15.1 per million in white Americans (5). Among children, the disparity was even greater: African American children were over four times as likely to die from asthma as were white American children (7). In the Northeast, Hispanics had a death rate of 34 per million (8).

Hospitalizations and emergency room visits for asthma demonstrate the disparity in the impact of asthma among different racial and ethnic groups. African Americans have an annual rate of hospitalization of 35.5 per 10,000, nearly four times that for whites (10.9 per 10,000). African Americans are approximately five times more likely than white Americans to seek care for asthma at an emergency room (5).

Health Impairment from Asthma Not Fully Captured by Hospital or Emergency Room Visits

These measures—rates of death, hospitalization, and emergency room visits—give an incomplete picture of the true burden of asthma in the United States. For example, one study found that children were nearly 10 times more likely to suffer symptoms of asthma on a given day than to visit an emergency room (9). Asthma symptoms that are not severe enough to require a visit to an emergency room or to a physician can still be severe enough to restrict activities and affect quality of life. Asthma is one of the leading causes of school absenteeism, accounting for over 10 million missed school days annually (10). Over one-third of people with asthma restrict their activities due to the disease (11). Asthma also accounts for many lost nights of sleep, disrupts family and caregiver routines, and causes additional social and economic consequences, including lost work days and job loss (12, 13, 14, 15).

Cost of Asthma to the U.S. Economy over Six Billion Dollars Annually

Estimating the costs of asthma is an indirect way to measure its health burden. In 1990, the cost of asthma to the U.S. economy was estimated to be $6.2 billion, with the majority attributed to direct medical expenses (12). A 1996 analysis found the cost of asthma to be $14 billion (16). Although different data sources were used, these reports are consistent with a rapidly increasing financial burden—even allowing for inflation. At this level, the direct medical costs of asthma comprise between one percent and three percent of all health care expenditures in the United States.

The Science of Asthma

Over the past 15 years, biomedical research has produced major advances in the understanding of asthma. Asthma is now known to be a disease of airway inflammation resulting from a complex interplay between environmental exposures and genetic and other host factors. These findings have changed medical treatment and environmental management of asthma.

Based on an improved understanding of asthma, inhaled anti-inflammatory medications have become the mainstay of medical management for patients with persistent asthma. Development of new medications to treat and prevent the symptoms of asthma—based on new insights into the cellular mechanisms of inflammation—will offer options to tailor therapy to the individual patient and, hopefully minimize the possibilities of side effects.

In addition to improvements in medical therapy, better monitoring techniques now permit objective measures of lung function that are simple tools for patients and physicians to use in assessing asthma severity and monitoring changes in the disease. In a disease like asthma that varies considerably over time, and where changes in lung function can occur before symptoms develop, objective measures provide essential information for making decisions about adjusting medications.

The Environment, Indoors and Outdoors, Affects People with Asthma

In addition to improvements in the medical management of asthma, the environmental triggers of asthma attacks have become increasingly well characterized. House dust-mites, cockroaches, animal dander, and mold have been identified as the principal allergens that trigger asthma symptoms (17, 18, 19). Reducing exposure to these allergens has been shown not only to reduce asthma symptoms and the need for medication, but also, in some studies, to improve lung function (20). Environmental tobacco smoke is an important irritant that can trigger an asthma flare-up, and possibly potentiate the effects

of allergens (21). Upper respiratory viral infections have been identified as an important trigger for asthma exacerbations, especially among children (22).

People with asthma, both children and adults, have long been recognized as particularly sensitive to outdoor air pollution. Common air pollutants such as ozone, sulfur dioxide, and particulate matter, are known to be respiratory irritants and can contribute to an exacerbation of asthma symptoms. Air pollution also might act synergistically with other environmental factors to worsen asthma (23). For example, some evidence suggests that exposure to ozone and diesel exhaust particulates can enhance a person's responsiveness to inhaled allergens (24, 25, 26, 27). Whether long-term exposure to these pollutants can actually contribute to the development of asthma is not known. To date, little research has examined the role of "hazardous air pollutants", such as volatile organic compounds or metals, in the development or exacerbation of asthma, although this is an issue of increasing public concern[4].

Knowledge Exists to Successfully Manage Asthma in Most Patients

As a result of advances in the management of asthma, both the medical and environmental aspects, asthma is better understood and the knowledge exists to manage it better than ever before. The Guidelines for the Diagnosis and Management of Asthma ("*Guidelines*")—developed by experts convened by the National Institutes of Health (NIH) and summarized in a 1991 report—detailed four strategies for managing asthma that substantially reduce the frequency and severity of asthma attacks (28, 29).[5] The report changed common perceptions about asthma and its treatment by emphasizing the role of inflammation in disease development, noting the importance of objective monitoring of lung function, and stressing the need to establish partnerships between patients and health care providers through patient education. In 1997, an updated version of the *Guidelines* was released (30). It remains the world's most comprehensive, up-to-date source of information on asthma diagnosis and management. Following the *Guidelines*, most people with asthma should be able to lead an active life, generally free from asthma symptoms.

The Causes of Asthma and of the Asthma Epidemic Are Not Well Understood

Although the causes of the increasing rates of asthma over the past 15 years are not known, some clues exist. Atopy, the genetically inherited susceptibility to become allergic, is the most important predictor of a person developing asthma (31). A substantial research effort is underway to identify the genes responsible for susceptibility to asthma. Because the genetic make-up of the population changes slowly, genetic susceptibility alone cannot be responsible for the epidemic of asthma that has occurred in the United States over the past 15 years. Further work is needed to clarify how genetic susceptibility and environmental

[4] The Clean Air Act defines 188 "hazardous air pollutants," which include substances such as benzene, phosgene, and mercury, as distinct from the more ubiquitous "ambient air pollutants" (e.g., ozone and particulate matter). Hazardous air pollutants are those emitted from stationary sources of air pollution. While asthma-related research has been undertaken on several ambient air pollutants, far less information is available on the potential effects of hazardous air pollutants on people with asthma.

[5] Experts convened by the National Asthma Education and Prevention Program (NAEPP), coordinated by the NIH's National Heart, Lung and Blood Institute (NHLBI), published a first set of recommended *Guidelines* in 1991 in the Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma (28).

exposures interact to cause asthma. For example, reactions to high levels of particulates and other ambient air pollutants appear to have a genetic component. Factors such as the intensity of environmental exposure and the age of the person being exposed are likely to be important. Many studies have demonstrated that exposure to indoor allergens is a risk factor for more severe asthma (32, 33). Some studies suggest that indoor allergen exposure is a risk factor for the initial onset of asthma (34). Individuals now spend more time indoors, thus increasing exposure to indoor allergens and pollutants.

Some of the same environmental factors that induce exacerbations of asthma have been postulated to cause the onset of the disease in previously healthy people. These environmental factors are house dust-mite, cockroach, mold, and other indoor allergens, and environmental tobacco smoke. But other changes in lifestyle (18) or exposures that stimulate the immune system may also be significant. The diet during the prenatal period and early infancy (35), the pattern of respiratory infections early in life (36), and obesity, possibly due to decreasing rates of exercise (37), have all been suggested as risk factors for the development of asthma. In persons with asthma resulting from workplace exposures, clear relationships have been identified between the level of exposure to specific chemicals and allergens and rates of sensitization and symptoms (38)[6]. In some situations, elimination of exposure can lead to complete resolution of symptoms. These observations may prove to be useful in understanding how environmental exposures to certain chemicals and allergens might contribute to asthma in the general population.

Data Tracking Asthma are Insufficient

Public health officials need to understand changes in rates of disease in different locations or populations in order to target health services and public health programs where they are most needed, to help evaluate the success of intervention efforts, and to provide clues about risk factors. At the present time, surveillance of asthma—or the systematic collection and evaluation of data with which to track the occurrence and severity of the disease—is limited to analyses of ongoing surveys and data systems on health events such as mortality, hospitalization, and outpatient visits. These data are typically several years out of date when they become available, and only provide national estimates. With the exception of recent work in several States to examine hospitalization and emergency room visits for asthma, data that would allow comparisons among States or cities are available only for deaths due to asthma.

[6] Work related asthma accounts for at least 21% of all adult onset asthma (39, 40).

The Challenge of Asthma

Rates of asthma as well as the burden of this chronic disease are increasing, despite important advances in research. This paradox raises two distinct issues: the increase in asthma over the last 15 years, and the worsening measures of illness for those who already have the disease.

If there have been breakthroughs in understanding the mechanisms of the disease, why are rates of asthma increasing? One key reason is that the cause of the asthma epidemic in the United States, which is also affecting most industrialized countries, is not known. Further research is needed to clarify the genetic basis of susceptibility to asthma, and the biologic mechanisms that explain the interactions of susceptibility and other factors, such as environmental exposures, that lead to asthma. Understanding why asthma is on the rise should lead to strategies to prevent the disease from occurring in the first place.

If the tools exist to manage asthma more effectively, why are a greater proportion of people dying from the disease today than 15 years ago? One explanation for worsening indicators of disease is that advances in asthma management have not yet been widely implemented. Although progress has been achieved in professional and patient education in the past decade, and research has shown that effective patient education reduces the use of emergency services and improves quality of life, many health care professionals and people with asthma remain unfamiliar with the *Guidelines* (41). Various outstanding programs supported by federal and private funds have helped foster needed changes in medical practice and patient behavior, but these need to be tested in a greater variety of settings and implemented on a larger scale in order to have national impact. Populations and neighborhoods experiencing the greatest burden of disease often lack access to high quality medical care, including adequate education about asthma managment and sufficient medications and equipment. In addition, lack of asthma surveillance at the State and local levels hampers public health efforts to direct quality health care toward the most severely affected populations.

Results of a mid-course evaluation of progress toward Healthy People 2000[7] goals for asthma were disappointing. The challenge of accelerating progress and achieving goals being set for 2010 is substantial, but the foundation for doing so is well established. We are getting closer to understanding the causes of asthma and the asthma epidemic. Expanded research, particularly in understanding the interaction between genetic susceptibility and environmental exposures, will yield the answers. The tools for managing asthma as a chronic disease have been assembled. With renewed effort—including wider dissemination of programs to promote adoption of the *Guidelines*, the development of robust surveillance systems, and evaluations of outreach and education programs—these tools can be continually refined and more widely implemented.

[7] Healthy people is a national prevention initiative that identifies opportunities to improve the health of all Americans. For two decades, the U.S. Public Health Service has used Healthy People reports to set specific objectives for health in targeted populations, to organize concerted action among the public health and private sectors to meet them, and to provide indicators for monitoring progress. Healthy People 2000 had three objectives specifically relevant to asthma: reduce hospitalizations, reduce activity restrictions, and increase the proportion of people with asthma who receive formal patient education.

DHHS Capacity to Address Asthma

In Fiscal Year 1999, the Department of Health and Human Services (DHHS) is investing approximately $120 million in research on asthma. Much more will be spent on health services delivery. Estimates of Medicaid and Medicare expenditures for treatment of asthma exceed one billion dollars per year (42). Thousands of people receive care for their asthma at DHHS-funded clinics and hospitals, but estimates of expenditures on asthma alone are impossible because costs are covered by large block grants that are not disease specific. To date, relatively few DHHS dollars—under five million—have been spent on public health practice for asthma[8].

DHHS is uniquely positioned to enhance the scientific knowledge required to prevent the onset of asthma and to improve the quality of life for millions of asthma patients and their families. DHHS-supported grantees have been responsible for many of the scientific breakthroughs that helped shape the *Guidelines*. The Department also funds research to study the quality of care received by individuals with asthma. DHHS could expand its evaluation of asthma care, as well as its efforts to track the disease, to more fully insure that appropriate and timely interventions are routinely provided, particularly to those in greatest need.

The Department has supported—and could substantially expand— model programs and partnerships that are discovering new ways to increase dissemination and use of information about how to manage asthma to communities, health care providers, patients and their families. Several DHHS agencies have undertaken activities on an exploratory basis, while others have the capacity for public health practice activities on asthma but have not yet made substantial investments. Expanded collaboration at the local level will facilitate progress in eliminating asthma-related disparities. Such progress is particularly relevant to DHHS' initiative on Eliminating Racial and Ethnic Disparities in Health, and to the focus of Healthy People 2010, the Nation's health objectives for the 21st century. (Appendix E describes in detail the asthma-related activities of DHHS agencies.)

Secretary's Initiative on Asthma

In the fall of 1997, DHHS Secretary Donna Shalala called for an initiative to tackle the growing problem of asthma. Shortly thereafter, the Interagency Task Force on Environmental Health Risks and Safety Risks to children, which Shalala co-chairs with Environmental Protection Agency (EPA) Administrator Carol Browner, began to address the environmental influences on childhood asthma. In April, the Secretary's Science Advisor (the Deputy Assistant Secretary for Science Policy) convened an intra-DHHS workgroup to help guide a Department-wide initiative on asthma, including but not limited to environmental aspects of asthma in children. The Workgroup generated a "statement of the problem" characterizing the asthma epidemic, a program-level inventory

[8] Public health practice activities are those that facilitate the work of the medical community and others to prevent asthma cases, reduce the severity of symptoms and improve the quality of medical care. Public health practice typically includes the development of educational materials, training and coalition building; and it could also include work with State and local environmental agencies. Public health practice is distinct from, but complementary to, direct provision of health services.

of current DHHS activities related to asthma, and a working list of proposals for how to meet the most urgent needs in asthma. At a full day workshop in June 1998, the Workgroup set four priorities for substantial investment over the next five years.

- ➢ Determine the causes of asthma and develop interventions to prevent it from developing in the first place.
- ➢ Reduce the burden for people living with asthma.
- ➢ Eliminate the disproportionate health burden of asthma in minority populations and those living in poverty.
- ➢ Track the disease and assess the effectiveness of asthma programs.

The strategy envisions close coordination between DHHS initiatives and activities led by universities, non-governmental and community-based organizations, private industry and other government agencies in pursuit of progress in these areas over the next five years.

The remainder of this strategic plan expands on these priorities. For each, it provides examples of current and relevant DHHS-supported activity to illustrate the breadth and depth of work underway, as well as the most urgent needs for additional investment. The plan concludes with detailed recommendations for activities to be undertaken in each priority area over the next five years. The recommendations represent the most urgent needs to control asthma and DHHS' capacity to address those needs.